



A Guide to Long COVID and Mental Health

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Coronavirus post-acute long-term effects: constructing an evidence base

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Introduction

This document grows out of the CONVALESCENCE Long COVID project. Many study members spoke about their mental health challenges, inspiring us to produce this Long Covid and mental health guide.

Long COVID can have many long-lasting implications on both your physical and mental health. It is important to focus on your mental wellbeing as it can help you better cope with the physical struggles of Long COVID. This may help you to better focus on relationships, day to day activities, life satisfaction, and yourself.

This guide is intended to:

- Support Long COVID patients with mental health resources, tools and techniques that have helped others – though **it's worth remembering that not everything will work for everyone, and anything mentioned in this guide is intended to be used as a recommendation, not enforced prescription**
- Help families and friends to understand Long COVID and its invisible effects on mental health, and how to start a conversation as an emotional support network
- Inform universities and places of work on what kind of help and support students and employees with Long COVID might need.



Individualised recommendations and support

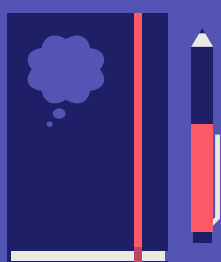
Below are mental health suggestions for individuals with Long COVID. Recommendations have been broken down into specific mental health categories with special consideration of the effects of Long COVID.

Depression

To help treat any symptoms of depression try:



Maintaining a daily routine to your best ability



Keeping a mood diary

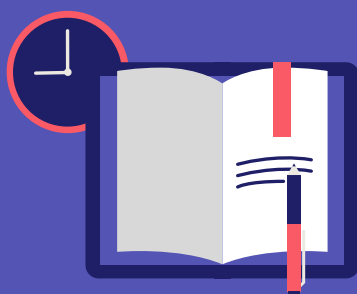
This is a journal or notebook where you write down changes in your mood everyday



Joining support groups



Practising a mindfulness and meditation technique called visualisation



Setting a 'worry time'

If you are worrying about things, write them down and come back to these worries only at a particular time of day, for an allotted amount of time (e.g., around 15 minutes).



Gradually starting to do things you enjoyed before you were ill, like gardening or DIY

Practising mindfulness meditation including mindful breathing exercises and the NHS Be Mindful online course

Mindfulness is a form of meditation in which you focus on your thoughts, senses, and body in the present moment – there are many apps and videos you can find that can walk you through how to practise mindfulness meditation



Setting yourself a realistic plan for the day, with small goals that will give you a sense of accomplishment.



Anxiety

To reduce anxiety try:



Participating in small activities
(health permitting)



Eating a healthy diet



Maintaining a daily schedule



Meditating



Cutting down on caffeine
and alcohol



Joining support groups.



Breathing Exercises

Breathing Exercises can be a useful way to cope with anxiety and panic, particularly as anxiety can be triggered and made worse by Long COVID breathing difficulties. There are many techniques to deal with breathlessness. You may want to try them all and then use what works best for you.

NHS exercises

General Breathing Technique. Find a comfortable position, breathe in deeply – you should feel your breath in your stomach. Count 3-5 seconds for each breath or however long is comfortable for you, try not to pause between breaths, do this for 3-5 minutes.

Physiotherapy for Breathing Patterns Disorders

Standing Breathing. Stand straight with relaxed shoulders and arms placed comfortably at your side. Breathe in and out through your nose – you should feel your ribcage rhythmically expanding as you breathe in. Please see videos and guides in the above link.

Exercises for breathlessness

- Rectangle Breathing Technique. Focus your sight on a rectangular object, follow the edge of the rectangle breathing out on the long side and in on the short side
- Seated Breathing. If you are sitting in a chair perch on the edge on the chair, lean forward placing your forearms onto your knees and breath
- Breathing Control. Sit comfortably in a chair with your back lightly resting against the chair, place one hand on your chest and one hand on your stomach, slowly breathe in through your nose for a count of 2 and out through your mouth for a count of 3
- Blow as you go. Breathe in before you make an effort, and then breathe out as you exert yourself – for example, when walking up stairs or picking an object up.

Social Anxiety

Managing social anxiety can be particularly difficult when you are also experiencing Long COVID. There are a number of COVID-19 related stress factors surrounding social situations.

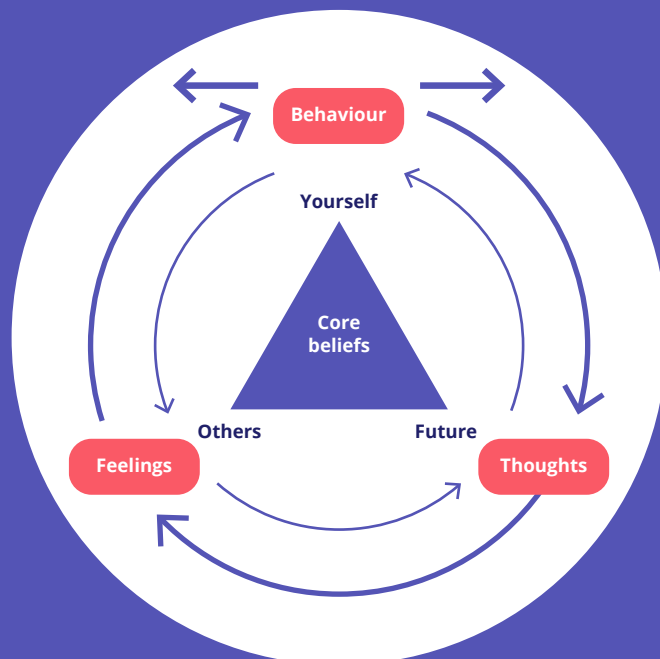


It can be helpful if you:

- Don't completely avoid situations that cause you anxiety
- Try to gradually increase the number of times you involve yourself in social situations
- Try to gradually increase the amount of time you spend in social situations
- Discuss and be open with your friends and family about your anxieties regarding social situations and the spread of COVID-19
- Break down social situations into smaller parts and work on feeling more relaxed with each part.

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) is a form of talking therapy that can help you better manage chronic symptoms of Long COVID. CBT is not a cure, instead it recognizes that your thoughts, feelings, physical sensations, and actions are interconnected and can help reduce depression and anxiety. Research has specifically shown that CBT has had considerable success for individuals suffering from chronic illnesses.



You can find more information about CBT [here](#) on the NHS website. To receive CBT you can talk to your local GP for a referral or find a therapist who specialises in CBT through the [NHS](#) or the [British Association for Behavioural & Cognitive Psychotherapies](#).

PTSD

Individuals who have Long COVID are at a higher risk of experiencing PTSD (Post-Traumatic Stress Disorder). Studies have shown that PTSD is not linked to how severe your illness was. If you feel you might be experiencing symptoms of PTSD, talk to your GP and read through the following recommendations. Although there are often long waiting lists for such services, you may find gaining access to them helpful.

Exposure Therapy

is a form of therapy that is particularly useful if you are suffering from flashbacks. Exposure Therapy allows you to experience your trauma through simulation (such as description or virtual reality) to learn how to cope with stressful thoughts, feelings, and memories.



Cognitive Processing Therapy (CPT)

is a specific form of CBT that has shown success for individuals with PTSD. CPT helps you manage your automatic thoughts and modify or change unhelpful beliefs. This is achieved through writing a detailed description of your trauma, and then talking with a trusted therapist about your ways of thinking about your trauma. CPT can be conducted through group sessions or individually.

Eye movement desensitisation and reprocessing (EMDR)

can help you manage your symptoms of PTSD. This involves recalling your traumatic memories, whilst engaging in routine side-to-side eye movements following the movement of the therapist's finger. Other methods may include listening to rhythmic taps and tones. It may help you change the negative ways you think about the trauma of a particular experience.

General Mental Health Recommendations

Diet and supplements

Individuals who have Long COVID are at a higher risk of experiencing PTSD (Post-Traumatic Stress Disorder). Studies have shown that PTSD is not linked to how severe your illness was. If you feel you might be experiencing symptoms of PTSD, talk to your GP and read through the following recommendations.

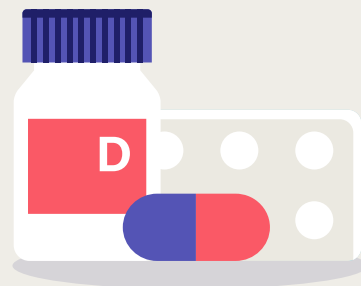


Drinking 2-3 litres of water per day



Cutting down on caffeine and alcohol

Taking supplements of:



- A multivitamin and mineral supplement may help if you are only able to eat small amounts
- Vitamin D is required for bone and muscle health, as well as immunity. A supplement of 400IU is recommended by the British Dietetic Association, especially if you are unable to get out of the house.

Sleep

Rest is important for both your physical and mental health. Current research shows that having excessive sleep does not usually improve the symptoms of Long COVID and that sleeping during the day can stop you from sleeping at night.

Try:

- Not spending too much of your time in bed
- Listening to your body
- Finding ways to rest besides sleeping
- Small regular moments of rest.

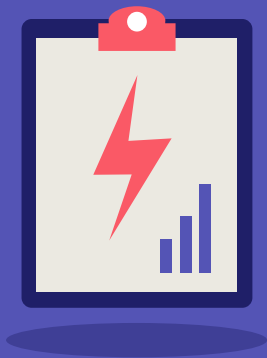


Exercise / Pacing

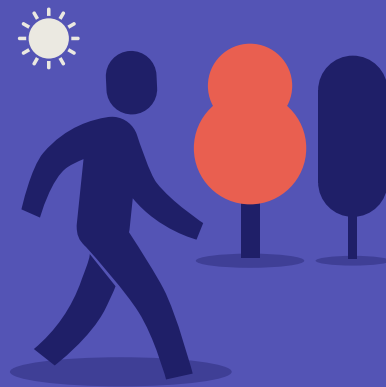
Exercising can be difficult to manage with Long COVID. It is important to not over-exert yourself when trying to resume normal activities. Pacing is a technique that helps you better manage your physical and mental energy by breaking down activity into small manageable chunks.

There are two main types of pacing: Symptom contingent pacing and Quota-contingent pacing. You can find out more about which type of pacing might work best for you [here](#). Symptom contingent pacing is driven by perceived symptom levels, with the aim of avoiding symptoms. Quota-contingent pacing refers to undertaking activities, according to an amount/distance/goal, aiming to gradually increase activity and improve functioning.

Mapping out the amount of energy (high, medium, low) certain activities require.



Balancing using your energy for essential and pleasurable activities



Keeping an activity diary (keeping a diary of your daily exercise and activities)



Trying small amounts of exercise – research shows it releases endorphins which can relieve pain, elevate your mood, and improve memory and concentration.

Accessing mental health services from the NHS

Although there are a lack of mental health services specifically for people with Long Covid, there are multiple ways to access mental health services through the NHS. These are four possible routes you could use to access care:

- Local GP Referrals
- NHS Mental Health [Hotline](#) (England Only)
- Finding an NHS [Psychotherapist](#)
- [Hub of Hope](#).





Support from family and friends

Talking to family and friends about mental health can be cathartic, and an important type of support. It's important to listen and believe loved ones when they say they are struggling. People with Long COVID often struggle to have their symptoms and feelings validated or believed in medical settings – being able to know they have the support of their loved ones can help with feelings of depression and anxiety.

Emotional support doesn't mean you have to get emotional. Especially for older people, and Long COVID patients who experience chronic fatigue or have impaired mobility, supporting day-to-day living is also important. This support can include:

- getting groceries
- cooking and household chores
- childcare for families with young children.



Remember that it's normal to feel grief, whether you are grieving because you feel a loved one has changed, or the way you live might have changed. That's why it's important to be open to talking and listening, as well as learning how to adjust to new ways of living.

Community support

There are lots of online groups you may want to explore for obtaining community support, advice and further recommendations. These do require web access or a smartphone. Below are a few examples:

Facebook groups

- [Covid Long Haulers Support Group](#) (public group)
- [COVID-19 The Long Haulers](#) (public group)
- [COVID LONG HAULERS SUPPORT](#) (public group)
- [Long Covid Support](#) (informative page with the latest developments in Long Covid treatment)
- [Long Covid Support group](#) (private group) (hosts weekly social and wellbeing Facebook events with over 52,000 members)
- [Long Covid Recovery UK Resources and Events](#) (public page advertising online resources, research and free virtual events within the Long Covid community)

Reddit groups

- [r/covidlonghaulers](#) [r/coronavirus](#) [r/COVID19positive](#) [r/cfs](#)

Twitter hashtags

- [#LongCovid](#) [#chronicillness](#) [#LongHaulers](#) [#pwme](#)

Twitter users

- [@Long_covid](#)

It is important to beware of the spreading of misinformation and the promotion of scam 'alternative medicines'. Never enter your card/bank details into a website you do not trust or follow links to websites with security warnings.

Helpful websites

Longcovid.org

Runs the Long Covid Support Group on Facebook

Yourcovidrecovery.nhs.uk

A comprehensive website detailing services and resources for Long Covid in the UK. Features mental health advice for patients and their carers

Icusteps.org

A registered charity run by former intensive care patients and relatives, improving the care and support available to patients recovering from critical illness during their long recovery

Carersuk.org.uk

Advice, information and support for carers and young carers with caring responsibilities

nhs.uk

The NHS website for England, providing information on health, treatment and services

nhsinform.scot

The NHS website for Scotland

Wales.nhs.uk

The NHS website for Wales

Hscni.net

The Health and Social Care website for Northern Ireland

Youngminds.org.uk

A comprehensive site supporting the mental health of young people in times of crisis

Otforlc.com

Cognitive pacing and energy conservation for fatigue management advice for Long Covid patients (including children and young people)

Longcovidkids.org

Advice for children and young people living with Long Covid

Longcovidwork.co.uk

Advice and support those staying in, returning or leaving work.



Financial support available in the UK

If you are employed, you may be eligible for Statutory Sick Pay (SSP). If you're not eligible or your SSP ends, you may be able to apply for Universal Credit or Employment and Support Allowance (ESA) if Long COVID affects how much you can work. ESA can help with living costs and support to get back into work if you are able to. You can also apply for Personal Independence Payment (PIP), which replaces Disability Living Allowance, if you have difficulty with everyday tasks and getting around.

If you're in England you can get a health and social care assessment to find out what help you can get (for example equipment, home care, day centres) from your local council. For more detailed information visit: www.gov.uk/guidance/find-help-and-support-if-you-have-long-covid

This page also outlines all disability related benefits: <https://www.gov.uk/financial-help-disabled/disability-and-sickness-benefits>

Please also see the following page from Citizens Advice: <https://www.citizensadvice.org.uk/benefits/>

Confidential helplines for urgent mental health help

- 116 123 to talk to Samaritans, or email: jo@samaritans.org for a reply within 24 hours
- Text "SHOUT" to 85258 to contact the Shout Crisis Text Line ([service ran by Shout 85258](#)).

International websites

- longcovid.org

Advice for students for obtaining university/ school support

Disclosing your condition to your school or university can lead to you obtaining extra support and concessions. Most universities require a copy of a report or letter from your doctor or consultant. Talk to the Disability Services at your university to find out what is expected.

Universities may also recommend you apply for Disabled Students Allowance (DSA) which could be helpful for assessing the disability-related study support required. DSA provides practical rather than financial support (this may be equipment, assistive technology software, psychological support and so forth). For more information, please go to: www.gov.uk/disabled-students-allowance-dsa



Advice for healthcare professionals

Medical advice

Encourage patients to keep a record of:

- Their goals and what they would like to achieve
- Changes in their symptoms
- The progress they are making in their goals
- How they feel their recovery is going
- Their symptoms – for example by using a symptom tracking app.

Ensure they have the contact numbers of who they can contact if they are worried about their symptoms or require more support.



Advice for employers

Symptoms can come and go as well as get better or worse over time. The usual rules for sickness absence and sick pay apply when someone is off work because of Long COVID.

ACAS, an independent body funded by the government to provide advice on employment rights, [states](#) that employers should:

- agree how and when to make contact during any absence
- make sure their work is covered and shared out appropriately while they're off
- talk about ways to support them as they return to work where and when possible.

The employer should talk with the employee about any support they may need. They could discuss:

- getting an occupational health assessment
- making changes to the workplace or to how the employee works, such as different working hours
- a phased return to work
- what they want to tell others at work about their illness.



Employers should make sure they have done everything they can before considering a capability procedure. If an employer dismisses an employee without first carrying out a full and fair disciplinary or capability procedure, the employee could make a claim of unfair dismissal to an employment tribunal.

Advice for universities

As of August 2021, over 106,000 under-25s are living with Long COVID [in the UK](#). Supporting students means listening sensitively and non-judgmentally and signposting them to sources of help within the university, for example, mental health support services. Heads of Departments should also be informed and educated on Long COVID and therefore be able to grant concessions and extensions for students with Long COVID.

Additionally, universities can encourage students to be assessed for DSA (Disabled Students Allowance).



We hope this guide can help you and your mental health.

We would like to thank members of the CONVALESCENE project PPI group at the University of West England for reviewing and commenting on this document and John Kellas for facilitating this.

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<https://www.ucl.ac.uk/covid-19-longitudinal-health-wellbeing/long-covid-and-mental-health>

Cohort studies:

